

# Project/programme report on results 2010-2013

TEMPLATE

## 1. General

- 1.1 Name of grant recipient: Atlas Alliance,  
1.2 Agreement number: QZA-09/265  
1.3 Agreement period: 2010-2014  
1.3 Local partner(s):  
Belgium: IF, International Federation for Spina bifida and Hydrocephalus  
Tanzania,  
- Dar es Salaam: Association for Spina Bifida and Hydrocephalus Tanzania (ASBAHT), Muhimbili Orthopedic Institute (MOI)  
- Moshi: CCBRT Kilimanjaro in cooperation with KCMC  
- Arusha: Arusha Lutheran Medical Centre (ALMC)  
Kenya, Kijabe: Bethany Kids at Kijabe Hospital  
Uganda  
- Kampala: Katalemwa Cheshire Homes, Central Uganda Spina Bifida and Hydrocephalus Network (CU-SBH) and the Spina Bifida and Hydrocephalus Association Uganda (SHA-U)  
- Mbale: Cure Children's Hospital Uganda  
- Mbarara: OURS  
Zambia, Lusaka: Beit CURE Hospital Lusaka  
Malawi, Blantyre: Queen Elisabeth Central Hospital in cooperation with Beit CURE International Hospital  
Sudan, Khartoum: Spina Bifida Federal Association
- 1.4 Norwegian partner: RHF  
1.5 Name of project/programme:  
Early intervention, treatment and rehabilitation of people with Spina Bifida and/or Hydrocephalus in Eastern, Central and Southern Africa

## 2. Reporting on Results:

- 2.1 What are the most important results achieved in the period 2010-2013?  
Please also explain briefly why this/these result(s) are the most important ones.**

*Keep in mind:*

- that this should be achieved results for the end users.
- that objective documentation of achievements, for instance from external evaluations is valued here
- gender
- comment on trends and tendencies that affected the achievement (adoption of legal framework/policies/UNCRPD etc, changes in the political environment, tendencies among mainstream actors to include disability)

Feel free to use a log-frame OR highlight the results and indicators as shown below.

### **Expected result 1:**

Strengthening of the parent and user groups by professionalization of organisational structure and improving knowledge level

### **Achieved result 1:**

During the program period all support groups have been empowered and are now stronger and more visible. Many support groups have established multiple branches nationwide, such as Kenya (13), Tanzania (7) and Zambia (3). This enables them to reach out to more parents, including those in rural areas.

In Kenya, Zambia and Uganda there are now registered *national* umbrella organizations, joining all district/local branches. This strengthens their position as DPO within the disability movement in their country. The Tanzanian DPO (ASBAHT) is in the process of setting up a national office with national board. In November 2014 they organized a 3-day workshop for all branch leaders to discuss the new constitution and joint activities. This constitution was approved in April 2015 during a general meeting. ASBAHT now consists of 7 branches and a national office/board.

The 4 separate Uganda support groups have joined hands and set-up a national umbrella association in order to align their strategies and advocate jointly on national level. Since 2014 the Central Uganda DPO and National umbrella association in Uganda are now a direct partner with own funds, instead of being supported/funded through our medical partner.

2 DPOs have become official members of IF's worldwide network; Sudan and Kenya. The president of the Zambian DPO is currently board member of IF.

The annual workshops organized by IF are well attended each year by support group representatives, and supports them with trainings on relevant topics, as well as provides opportunity for South-South networking. In 2014 it was decided to organize these workshops only biannually and organize project visits in the other years to enable more direct and project-specific support to the partners. Therefore 2014 did not have a workshop.

### **Indicators of achieved result 1:**

Indicator	Baseline (2009)	2010	2011	2012	2013	Progress from baseline	2014
# parent meetings	83	89	109	111	134	+ 61,5 %	146 (+76%)
# parents reached	2.568	3.620	3.443	4.661	4.643	+ 81%	5.139 (+100%)

### **Expected result 2:**

Improvement and sustainability of access to (knowledge of) medical care and lifelong care for the target group

### **Achieved result 2:**

Each year more children are identified, which is direct evidence of the success of the program, but also of the continuous need for more service providers. The challenges remain for our partners to provide services to the growing number of children with SBH and the limited resources available, both human and financially.

Great progress has been made and partners are collaborating with other health care facilities to fill some of this gap. Government-owned public hospitals in Dar es salaam, Tanzania and Mbarara, Uganda have started a program for SBH children in collaboration with our partners. Operations are done in satellite and partner hospitals in Malawi, Zambia and Tanzania.

Through IF's partner CURE International, new neurosurgeons in Tanzania, Malawi and Kenya (both public hospitals) have been trained in the advanced treatment for Hydrocephalus, and are linked up with IF and its local partners to become part of the network of service providers. In 2014, the neurosurgeon from Mbarara Regional Referral Hospital in Uganda was also trained in this technique. This hospital is now closely collaborating with our CBR partner to provide coordinated medical and lifelong care closer to the homes of the families.

The development of the S.H.I.P. model facilitates this collaboration, as it provides a framework for services and collaboration.

The multidisciplinary care model S.H.I.P. is unique in its kind as it brings all stakeholders around the table as equal partner in the care of the children. It is meant to improve coordination and collaboration between partners towards an individualized care program - both medical and lifelong/rehabilitative -, meeting the specific needs of the child. Such a personal approach will in the long term contribute to the improved quality of life of people with SBH.

While medical care is now more widely available, the knowledge and services for lifelong follow-up are still mainly situated at our current CBR partners. More efforts are needed to network and collaborate with other existing CBR providers.

### Indicators of achieved result 2:

Indicator	Baseline (2009)	2010	2011	2012	2013	Progress from baseline	2014
New children with SBH (per year)	2.302	2.282	2.459	2.725	2.976	+ 29%	3.010 (+31%)
Total children in program	11.952	12.594	16.712	19.684	21.592	+ 80,6%	23.785 (+99%)
with SB (with/out HC)	4.499	4.273	5.484	7.241	7.877	+ 75%	8.629 (+92%)
with only HC	7.453	8.321	11.228	12.443	13.715	+ 84%	15.156 (+103%)
# shunts placed	1.168	1.593	1.946	1.839	1.652	+ 41,4%	1.603 (+37%)
# ETVs performed	445	473	571	695	619	+ 39%	700 (+57%)
# SB operations	349	426	693	490	595	+ 70,5%	665 (+90.5%)

### Expected result 3:

Establishment of a sustainable program to promote independence of youth and youth as advocates to peers, community, health organizations and authorities

### Achieved result 3:

Due to the success of the program, and the survival of children, there is now a growing group of youth and young adults, who are also becoming more active within the DPO. Youth meetings and trainings are organized and form a good basis for these young people to become role models and advocates for the rights of people with SBH.

Youth groups are established in all partner countries.

Youth has been represented during the African workshops in 2011 and 2013, where they provided important input in the development of Youth Advisory Councils (YAC) and the S.H.I.P. model. YACs are set up in Kenya, Uganda and Zambia.

Through Facebook an international youth and adults group has been formed, which is called Global Friends, where people with SBH can find each other online and share experiences, questions and advice.

First steps towards the development of a life span tool have been made. Efforts are now planned for the fall 2014 to finalize this and start implementation soon thereafter.

A workshop on transition/adult management was organized in Kenya in August 2014, where our local partners worked together to develop a model for a transition clinic to be piloted in Kenya. This model aims at providing services addresses the changing (healthcare) needs of persons with childhood-onset disabilities as the individual grows from a child to youth, from youth to young adult, and from young adult to adult.

An inventory of youth and young adults is currently being made and a coordinator is in the process of being hired. Funding for this coordinator has been secured for the next 2 years (2015-2016) through other sources of funding.

In addition, the Growing Up Ready timetable (*see picture below*) was translated to African setting and is being piloted within the above-mentioned transition pilot at the moment.

A first evaluation of this pilot project is planned for fall 2015.

	INFANCY	CHILDHOOD	PRE-TEEN YEARS	ADOLESCENCE	ADULTHOOD
<b>medical</b>	love & care health & food mobility hope for the future be active in your child's care ask questions share your concerns find a doctor/ centre for care	know my body bowel & bladder continence skin care teach your child about his/her disability talk to your child about his/her physical needs go for medical check-ups and follow up!	friendship & fun school & life education do I understand my teacher? learn about puberty get information when there is a gap in knowledge ask questions when you don't know	school & life education friendship & fun work & play start making your own appointments come to appointments with questions & concerns order your own medications and B&B equipment start looking for adult rehab services learn about sexuality & family planning	sexuality future & family planning adult rehab make your own appointments transfer to adult care if possible keep your own medical file
<b>physical</b>	mobility at home encourage developmental milestones ensure prevention and/or treatment for deformities find support from a Physiotherapist or Occupational Therapist	use physical exercises to strengthen his/ her physical abilities and avoid deformities find or invent mobility aids/orthesis encourage full use of physical abilities to be as mobile as possible	learn about your physical potential and use it for your mobility encourage physical exercises for strengthening and prevention of deformities encourage use of orthesis and mobility aids	use your mobility aids/orthesis learn to do your regular exercises to remain as self-reliant as possible in mobility participate in play activities with peers	regular exercises to remain as self-reliant as possible in a life-time job use your mobility aids, maintain them and visit your service provider when they are grown out or need repairs
<b>self care</b>	allow your child to feed itself check for insensitive skin (feet) keep child clean & dry take breaks from your baby start bladder and bowel care	teach healthy eating habits be vigilant about skin care (avoid early scarring) teach bladder & bowel care	cook together encourage skin care especially for your bottom learn life skills & how to manage money be fully in charge of bowel & bladder care if possible	be active & eat well do all your own skin & personal care learn to ask for support when you need it do all your own bowel & bladder care	your health care is a life-time job keep looking for opportunities to be healthy participate in your community activities join your SB&H parent support group
<b>education</b>	socialize with your baby find supportive families and friends join a local parents' group use community based rehabilitation workers	let your child make choices give your child chores get ready for school, find a school, educate the teachers how will your child get to school? what assistance will there be at school?	encourage hobbies encourage leisure, sports & friends do your own homework find your special talent seek advice if you need special support at school (special education teacher, devices, personal care)	learn to advocate for yourself get involved at school make friends plan for after high school find volunteering or part time work opportunities	keep in touch with friends turn off the TV & get involved practice independence, money management & other skills start your own youth group be a role model for parents & young children

### Indicators of achieved result 3:

Indicator	Baseline (2009)	2010	2011	2012	2013	Progress from baseline	2014
# youth trainings & meetings	N/A	12	13	24	30	+ 150% (since 2010)	47 (+290%)
# youth in parent group committees	6	23	25	29	46	+ 666,7%	44 (+633%)

### Expected result 4:

Improvement of access to education, skills training and daily life activities for the target group (inclusion)

### Achieved result 4:

Continence training is seen as the most important training towards independence. It teaches children and their parents how to become socially dry, not smelling of urine and faeces, and being able to play with peers, go to school, and in general participate in society.

The continence program is continuously growing, and each year more children are starting catheterization. Communities and other service providers are increasingly involved in the program in order to improve compliance.

However, more efforts are needed to ensure children are continuing their program when they grow up, as we see a substantial number of children over 10 years dropping out. The reasons for this need to be evaluated, and are most likely multifactorial. The growing number of youth involved (see result 3.) will have an important role to play in this.

Our partners have actively been networking with schools, sensitizing them about SBH and supporting them to include children with SBH in their classes. Each year an increasing number of children are attending school for the first time.

#### Indicators of achieved result 4:

Indicator	Baseline (2009)	2010	2011	2012	2013	Progress from baseline	2014
New children in continence program	424	633	541	630	877	+ 106,8%	987 (+132,8%)
Total children in continence program	2.012	2.691	3.023	3.472	4.049	+ 101%	4.665 (+131,8%)
# children on CIC going to school for the first time	105	129	105	132	134	+ 27,6%	153 (+45,7%)
# schools in network	N/A	89	92	131	172	+ 93% (since 2010)	226 (+154%)

#### Expected result 5:

Improvement and sustainability of preventive measures and access hereto in relation to occurrence of SBH, advancement of disability, social acceptance, etc.

#### Achieved result 5:

As one of the causes of Spina Bifida is an insufficient level of folic acid, IF advocates to fortify flour with this important vitamin. In a public-private partnership (other donor), IF's flour fortification project provides technical support and training for flour millers as well as government food control staff, as both groups are key advocates in fortifying flour with vitamins and minerals.

Up till now great progress has been made, and flour fortification with micronutrients, including folic acid, is now mandatory in Uganda, Kenya and Tanzania. Specific logos are now printed on flour bags when these are fortified.

Fortification with folic acid can prevent up to 70% of neural tube defects.

The support groups in these countries have been involved in these above-mentioned trainings, during which parents and youth with SBH gave their testimonies on living with Spina Bifida. This has been found to have considerable added value and is highly appreciated by the participants.

Knowledge about the prevention of Spina Bifida through folic acid has also been largely disseminated within the communities through the support groups' activities, such as awareness walks, campaigns, short video, and other forms of training.

In 2014, our CBR partner in Moshi, Tanzania especially has made great efforts to sensitize public health facilities on folic acid as preventive measure for spina bifida, who have distributed the folic acid tablets. In 2013 they were one of the partners reaching out to the least number of women, and have now been able to reach more than 7.000 women through this system of health facilities. However, they have also noticed that folic acid tablets are still not always used correctly, and therefore more sensitization will be needed. They are planning to develop a poster on correct use and sources of folic acid.

In addition, it needs to be monitored to see if the number can continue to be at the same high level, given the fact that provision of folic acid is done indirectly, and therefore less controlled.

Sensitization on prevention through folic acid remains a continuous effort in the next program period.

#### Indicators of achieved result 5:

Indicator	Baseline (2009)	2010	2011	2012	2013	Progress from baseline	2014
# women receiving folic acid	3.499	2.386	3.354	5.974	7.000	+ 100%	15.585 (+354%)
# trainings on preventive measures	N/A	29	19	25	41	+ 41,4% (since 2010)	69 (+138%)

**2.2 In case predefined objectives were not reached, please name what factors (internal and/or external) were hindrances. Please describe what was done to tackle them.**

**Internal:** *(Administrative challenges such as: major changes within the organisation's structure? High staff turn-over? Commitment from the executive committee? Technical challenges: was the level of ambitions realistic? Was the risk assessment useful when the hindrances occurred? Was the monitoring and evaluation system user friendly and covered all information you needed? Did the organisation have the necessary competence to carry out the project or did you need to hire or train staff/members more to do what you set out to do?)*

**External:** *(political disturbances, violent conflicts, hyperinflation, floods, earthquakes, disease outbreaks of Ebola, etc?)*

All objectives have been reached, however we have seen an increased challenge for our CBR partners in maintaining the same activity level, due to loss of other major international donors as a result of the financial crisis. Although this has not affected our program as yet, it needs to be monitored and taken into account during the next program period.

**2.3 Has the realisation of the programme contributed to, or resulted in any unanticipated consequences (positive or negative)?**

No unanticipated consequences

**2.4 Which trends and tendencies have affected your project/programme the most during 2010-2013?**

*For instance: Has your organisation and its programmes worked systematically to promote or implement the UNCRPD, specific Millennium Development Goals (MDGs), or global initiatives like Vision 2020, or Stop TB?*

*If yes, how?*

*Do you see any change (positive/negative)? For instance regarding the UNCRPD: how is the relationship with the governments and your partners today compared with 2010? How does the civil society in general and media look at the rights of persons with disabilities? Are other NGOs more open to collaborate on rights of persons with disabilities now compared to in 2009/2010?*

*Please note: skip the question if you have already responded to it above.*

There is an international momentum to move the agenda of disability forward; recent UN initiatives have raised the profile/the importance of disability rights in general and birth defects more specifically: UN CRPD, UN High Level Meeting on Disability and Development, UNICEF's State of the World's Children report (2013), WHO WHA 66 resolution on Disability (2013), WHO WHA 63 resolution on Birth Defects (2010). These reinforce the work of IF and its local partners.

Articles 25 (Health) and 26 (Habitation and Rehabilitation) of the UNCRPD are crucial in the work of IF and its local partners. Children with SBH who do not have access to adequate healthcare services will have a worse outcome which will be reinforcing negative stereotypes on disability. This will result in a lower investment in healthcare for children with disabilities.

The program is mainly working on improving MDGs 4 (child mortality) and 5 (maternal health), but also 2 (primary education) and 8 (global partnership). IF works in many areas together with international organizations, which are linked to our local partners whenever possible. The involvement of our local partners in flour fortification initiatives are a good example of this. The program includes targeting schools in order to increase the number of children with SBH receiving education.

We see a positive change in the attitude of people towards SBH, as is demonstrated by the increasing number of families that find their way to health facilities; through referral by health care providers, identification by other families/villagers or self-referral after media attention. More

of these health facilities are governmental institutions, and the relationship between our partner and authorities is improving.

The World SBH Day in October, which was established in 2012, is celebrated worldwide and attracts a lot of media attention. This sensitization of society helps to reduce stigmatization and is an important step in mainstreaming SBH into programmes and policy.

**2.5 What has been the added value of the partnership of the Norwegian organisation? Summarize the Norwegian organisation's contribution to the partnership, besides the financial assistance.**

The benefits to the local partner organizations are the knowledge and coaching that RHF provides to them. As a DPO RHF has gone through all the organizational development stages itself, and shares this experience with the local DPOs, who are now undergoing these same steps. This parent-to-parent support is highly appreciated by the local partners, as they feel supported on all levels. This is an important aspect towards the sustainability of the local DPOs. End 2014, IF and RHF visited Malawi, where it was discussed and agreed with the Malawian parent group that they would become financially independent from our medical partner (QECH). RHF will support and mentor this group more intensively in order for them to grow as an organization.

In addition, the daily manager of RHF, an adult living with SBH herself, serves as a role model, coach and mentor to the youth and adults with SBH, as well as being an example of hope to the parents.

In 2014, a pilot project on transition in Kenya was started with the aim to provide adult services as a continuation of the already existing paediatric services. Many young adults are lost to follow up as they outgrow paediatrics while no adult service provider is available. By implementation of a program that follows a child from infancy and childhood to adolescence and adulthood (*transition clinic*), and develops necessary life skills throughout this period (*Growing Up Ready*), children, youth and adults with SBH can be adequately supported towards an independent and healthy life.

RHF, and more specifically their daily manager, has been very actively involved in the preparation of this pilot.

With IF as international partner organization, this adds both a complexity as well as an added value to the equation. IF is the global knowledge network on SBH, and RHF is part of that network. IF has years of experience in working with DPOs and the target group in developing countries, and has a large network of NGOs, health organizations and parents.

**2.6 To what degree has the programme been carried out in cooperation with other donors, international, national or local?**

1) IF's program on flour fortification is supported by the Dutch government, but connects with IF/RHF's program in many areas.

2) In Tanzania, IF is working with the Swedish government in the same program.

3) Over the years, most of the shunts to treat Hydrocephalus are now being supported by a Belgian NGO, Child-Help. On this level, RHF is gradually phasing out.

IF has created a working group International Solidarity, in which donors and experts are meeting to discuss progress and strategic priorities. Through this working group we ensure that all programs supported by various donors run in line with each other, with local needs and with IF's priorities. The working group meets at least twice per year.

**To what extent did they follow plans of the local authorities vs. attempting to influence local authorities?**

As all programs are strategically aligned, all include attempts to influence local authorities, either directly or through the local partners.

**2.7 Outline briefly how the programmes have contributed to strengthen civil society.**

The local partners have made great efforts to strengthen their position in society. Many new DPO branches have been set up, which increases visibility nation-wide, being able to reach more parents and lobby to the various local authorities and organizations.

The annual World SBH Day (since 2012) and the attention it has received from society, media and government puts SBH on the map and has made the local partners recognized experts in their field.

The S.H.I.P. model puts all stakeholders in care around the table as equal partners, emphasizing and strengthening the role of civil society, both parents and people with SBH themselves.

On prevention of birth defects, such as Spina Bifida, there has been ample networking with industry and authorities in order to proceed towards full implementation of the mandatory flour fortification laws in Kenya, Uganda and Tanzania.

## 2.8 What are the **most important lessons learnt** from the **running of the project/programme**? What parts should be changed and/or adjusted if any potential new agreement is entered into?

*Please consider some or all of these in your response:*

- *Project/programme approach: How has your project approach worked? Could you achieve the objective through the approach? Do you have all necessary information such as baseline study and informative and useful monitoring and evaluation (M&E) systems, and regular reports? How realistic was the original long-term plan? Have there been any significant changes during the period? Will you be changing type of programme or approach in the new long-term period?*
- *Sustainability: How have you been working on sustainability? Have you been experiencing any challenges or had any good achievements sustainability-wise?*
- *Thematic priorities <sup>1</sup>: Have thematic priorities changed during the period – if yes, why?*
- *Geographic areas: Has the geographic location(s) changed during the period – if yes, why?*
- *Collaboration/harmonisation with others: Have you seen a change in how, and with whom, you collaborate during the period? Please describe significant positive/negative experiences.*
- *Size of project/programme: Have the project/programme's scale been ok, too high, too low? Is there potential to scale up/down of some or all components?*
- *Gender: has it been possible to keep up the gender focus throughout the period? Planning, implementing gender-related activities, reporting on gender etc.*
- *Climate and environmental issues: has your project/programme been affected by climate changes and environmental aspects, or even disasters? If so, please elaborate on how this affected the running of the project.*

### **Project/programme approach:**

The need for people with SBH and their families to come together and share experience and knowledge is still great. The support group activities are therefore an important aspect of the DPO's work and will remain key objective.

Most DPOs are experts in their field and seen as such by service providers; there is growing collaboration in which DPOs take an important advisory role. Within S.H.I.P., the target group is acknowledged as an equal stakeholder.

With the increased knowledge within society and service providers, the professionals in health care take a more active role in establishing services for children with SBH closer to their homes. Partners are training other service providers in order to accomplish this. The S.H.I.P. concept helps in this, as it provides a framework and tools to facilitate communication, networking and collaboration.

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<sup>1</sup> education, health, rehabilitation/CBR, organisational development, research&documentation, gender

The S.H.I.P. coordinator is key to implementation of the S.H.I.P. program as he/she develops and supports the network, and ensures input from all stakeholders. However, we have seen that this position is also challenging and demanding. In projects where there is already a challenge with high staff turn-over, this is even more difficult. In the next program period, it will therefore be one of the key aims to ensure availability of a coordinator that is embedded in an existing support system.

The overall result of the project is very satisfying, as health care is currently more available and accessible than before the program period. The number of public service providers having SBH services has increased substantially.

The main challenge has been the rapid growth of the DPOs and the voluntary status of the people running it. Very enthusiastic and dedicated volunteers have greatly invested time in the further professionalization and visibility in general. This all comes next to their work and family life. To enable to continue this growth, the possibility for employed DPO staff needs to be evaluated during the next program period.

Data collection is still challenging for many partners. While IF/RHF has developed a system for this, which is being used by all partners, it has been found that some indicators were too difficult to collect.

There have not been any significant changes in approach during the program period.

**Sustainability:**

The development of S.H.I.P. contributes largely to the sustainability and eventually phasing out of the program, as standardization of care and increased collaboration between local organizations (public and private) is the key element of S.H.I.P.

S.H.I.P. will be a focal point for RHF/IF and all its partners for the following years.

Donor dependency for DPOs is improving, with some DPOs now finding funds from multiple donors. However, these funds are mostly activity-based and in-kind donations and are not covering the daily running of an organization. This will remain a focal area when strengthening the support groups, as more improvements towards sustainability are needed.

**Thematic priorities:** no changes

**Geographic area:** locations/countries have not changed.

**Collaboration:** during the program period there have been several changes in local partners; some were stopped, others added. Collaborations were stopped in Sudan and Zanzibar, where the partners were unable to comply with project management and/or quality requirements. However, these regions were not completely left; other existing partners are still active. However it is recognized that in these regions many services are still lacking.

**Size:** due to the success of the program, more children are seen each year as they now find their way to the health care facilities, and more primary health care centres are referring to our partners. Hence, the size of the program continues to increase. Unfortunately many partners see themselves at their limits of resources, both human and financially. Scaling up is needed, but only possible with additional resources. Through the S.H.I.P. model we hope to engage more partners, which would help in covering this by spreading services amongst a large network of service providers.

**Gender:**

As the incidence and prevalence of Spina Bifida and Hydrocephalus has no gender specificity, gender is by definition an integral and cross-cutting part of our program, interwoven with all our activities. All program activities are available and accessible for boys and girls, mothers and fathers.

Only the preventive measure of sufficient folate blood levels (i.e. folic acid) is gender specific to women, as the timely intake of folic acid by (expecting) mothers has proven to be the main preventive measure for Spina Bifida.

The access to medical care and follow up programs for boys and girls with SBH is based on need rather than gender and care is provided to both sexes. Although it is recognized that overall needs and challenges can be different for boys and girls, the need for a back closure in case of Spina Bifida, the need for a shunt in case of Hydrocephalus or the need for correct catheterization to become socially continent and participate in society, does not differ by gender. Within the area of inclusion, activities are focused on paving the way for children to be able to participate in society and on availability of infrastructural requirements, regardless of the gender of a specific child.

Within the DPOs it is mainly the mothers that are actively involved in the organization and activities of the support group. More and more these mothers are involved in providing expert training to their peers.

For our specific program and target group, it remains a challenge to involve the fathers in the care of their children. Experience has shown us that many fathers get more involved when it comes to organization building and parent groups. Fathers that are already involved in the DPO are actively encouraging other fathers directly to take their responsibility in the care of their children.

Through the building of parent groups, sharing of experience and positive examples, fathers are triggered and the situation of the family can change towards equality.

Expected result	Indicator	Baseline (2009)	2010	2011	2012	2013	2014
Equal involvement of mothers and fathers in parent group meetings	% women as chair PSG	50 %	53%	58%	55%	57%	52%
	# women : men in board PSG	33 : 27	64 : 37	73 : 41	80 : 40	76 : 43	96 : 48
	# mothers : fathers attending PSG meetings	N/A	2.645 : 488	2.830 : 613	3.857 : 804	3.783 : 860	3.922 : 1.217
	% women : men attending workshop	60 : 40%	58 : 42%	52 : 48%	N/A	55 : 45%	N/A
Mothers-as-experts programme	# mothers as trainers	N/A	55	28	48	41	93
Equal access to medical and lifelong care for boys and girls	% Boys : girls in follow up	N/A	55% : 45%	55% : 45%	56% : 44%	57% : 43%	57,5% : 42,5%
Equal working conditions for female health workers	# female staff paid	15	15	11	15	19	17

#### Climate/environment:

Poverty and environmental/ climate changes are inextricably linked, as the majority of the poor people, and with that also people with disability, depend on using natural resources for their livelihoods. Any negative change in climate can have a devastating effect on the availability of food, water and other sources.

The project has no direct influence on the environment, and no environmental factors have influenced the project more than usual.

The influence of the climate is related to the rain season. Heavy rain makes it even more difficult for families to travel to hospitals, health and CBR centres to seek the necessary care. This might result in children not receiving the care in time, with increased risk of further complications.

There has been suggestion that the prevalence of Hydrocephalus increases during rainy season, although more research is ongoing to determine the exact relation (*Schiff, Warf: Rainfall drives Hydrocephalus in East Africa, JNP, 2012*). Due to the complexity of this relation, we don't know yet how to cope with this problem and how to prevent the increase of HC cases. Note that this risk has not increased during the program period, it is a general risk related to the climate.

Date:  
Signed:  
Title: